DOCUMENT RESUME

ED 311 356 CG 021 971

AUTHOR	Craig, Rebecca T.
TITLE	Community Care for Persons with Serious Mental Illness: Removing Barriers and Building Supports. Human Services Series.
INSTITUTION	National Conference of State Legislatures, Denver, CO.
REPORT NO	ISBN-1-55516-239-8
PUB DATE	Oct 88
NOTE	12p.; Update of ED 273 908. A product of the Mental Health Project.
AVAILABLE FROM	Book Order Department, National Conference of State Legislatures, 1050 17th St., Suite 2100, Denver, CO 80265 ($5.00 book rate; add $1.50 for first class postage and same day handling).
PUB TYPE	Reports - General (140) -- Collected Works - Serials (022)
JOURNAL CIT	State Legislative Report; v13 n35 Oct 1988
EDRS PRICE	MF01/PC01 Plus Postage.
DESCRIPTORS	*Community Health Services; Cost Effectiveness; Federal Legislation; *Financial Policy; Financial Support; *Mental Health; *Mental Health Programs; *Public Policy; State Government; State Legislation; State Programs; *Trend Analysis

ABSTRACT

The mental health policies of the past 20 years and the evidence of unserved populations suffering from serious mental illness constitute a public health crisis. Currently there are at least 3,000,000 people in the United States suffering from mental disorders. A fully developed continuum of care is needed to respond effectively to the diverse needs of mentally ill persons at varying times in their lives. Acute and crisis psychiatric care, rehabilitative services, housing, and supportive services are required. These services/policies for the mentally ill should be provided: (1) specialized services in the community; (2) community mental health centers focusing more of their resources on services to those with serious mental illness that are not provided by other community agencies; (3) sufficient inpatient beds for long-term care and forensic units; (4) intermediate level care; (5) a single local agency assuming responsibility for planning and coordinating services; (6) efficient fiscal/management policies; (7) elimination of barriers to participation of the seriously mentally ill; and (8) research into the practical problems faced by legislatures. Future service and delivery systems must be revised to meet the changing needs of new and emerging populations. The future mental health system will continue to become more decentralized and efforts will be made to access services through broad-based programs such as housing, income support, and social services. (Specific state responses are described.) (ABL)

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MENTAL HEALTH PROJECT

Human Services Series

COMMUNITY CARE FOR PERSONS WITH SERIOUS MENTAL ILLNESS:

REMOVING BARRIERS AND BUILDING SUPPORTS

by

Rebecca T. Craig

Vol. 13, No. 35 Updated October 1988
An Information Service of the National Conference of State Legislatures
1050 17th Street, Suite 2100, Denver, Colorado 80265. William T. Pound, Executive Director

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(Vol. 13, No. 35) (ISBN 1-55516-239-8) November 1988

STATE LEGISLATIVE REPORT is published 12 to 18 times. It is distributed without charge to legislative leaders, council and research directors, legislative librarians, and selected groups for each issue. For further information on STATE LEGISLATIVE REPORT or to obtain copies, contact the NCSL Book Order Department in Denver at 303/623-7800.

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COMMUNITY CARE FOR PERSONS WITH SERIOUS MENTAL ILLNESS: REMOVING BARRIERS AND BUILDING SUPPORTS

INTRODUCTION

The deinstitutionalization policies of the 1960s and 1970s left many communities unprepared and unequipped to handle the needs of those with serious mental illness. They were unable to offer continued outpatient care for patients whose illnesses were characterized by relapses and acute episodes. Moreover, community programs were not able to supply all the services for which mental hospitals had been responsible, such as food, shelter, clothing and medical care. Mental health treatment and rehabilitation services for the chronically disabled were largely unavailable in many areas, leaving discharged patients with little or no follow-up care. In addition, many discharged patients were and are expected to negotiate a maze of service programs and providers that may or may not meet their needs.

A lack of systematic approaches for the financing of community-based services for the mentally disabled further exacerbated these problems. Funds come from various sources, which may or may not have administrative responsibilities; eligibility requirements may vary among jurisdictions, services, and populations; funding formulas are often complicated; and exceptions and exclusions further confuse the funding issue. Although federal supports devote significant resources to this population, certain aspects of these programs, such as fiscal incentives for unnecessarily restrictive care, continue to pose critical obstacles for individuals with serious mental illness and serve as disincentives to effective community care.

Government studies, media and consumers' reports and service professionals have decried the problems wrought by deinstitutionalization and community placement of persons with serious mental illness without adequate services. The mental health policies of the past two decades and the evidence of unserved populations suffering from serious mental illness constitute a public health crisis. Policymakers need to investigate the costs of providing--and not providing--services for those with serious mental illness in the community. Development of comprehensive services may appear expensive, but the present lack of such services also is costly.

WHERE ARE THE MENTALLY ILL AND WHAT SERVICES DO THEY NEED?

Problems in defining chronic mental illness, gathering reliable data and locating persons with mental illness create difficulties in determining the population's size. Currently there are at least three million people in the United States suffering from severe mental disorders. Of these three million, the 1.7 to 2.4 million who suffer prolonged, severe disabilities constitute the seriously or chronically mentally ill population. These people either reside in institutions or live within the community in a variety of residential settings (1, p. 5).

About 1,147,000 persons with serious mental disorders receive institutional care in mental hospitals or nursing homes. Approximately 120,000 are inpatients in long-term care settings, including state and county hospitals. An estimated 1,027,000 chronic patients reside in nursing homes (2).

The community population of individuals with serious mental illness numbers approximately 1,635,000. Services used by this population are more difficult to estimate because of the population's mobility and use of many services. Approximately 175,000 to 300,000 of those with serious mental illness live in community residential facilities, such as board-and-care and group homes. Another 1.1 million reside independently or with families, and another 125,000 to 250,000 are homeless (2).

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Like the general population, persons with serious mental illness need food, clothing, housing, medical and dental care, transportation, education, recreation, money, and a personal support system. However, because these individuals suffer from severe functional disabilities, they require distinct, specialized services to meet their unique needs at various times in their lives, including the following (3, pp. 232-234):

- o Shelter - an array of special living arrangements designed to provide temporary crisis stabilization, rehabilitation and long-term support;
- o Subsistence - assistance in meeting basic needs, such as food, clothing and spending money;
- o Medical and mental health care - adequate medical and mental health care, including personnel to work with specialized populations;
- o Crises stabilization - constant crisis assistance with the capacity for on-site assistance;
- o Evaluation - comprehensive, realistic evaluation of an individual's strengths and weaknesses for the development of plans to achieve goals;
- o Socialization - assistance in developing social skills and leisure time pursuits;
- o Daily living skills training - training in such areas as cooking, budgeting, transportation and personal hygiene;
- o Employment opportunities - job training and assistance in job procurement techniques; and
- o Continuous personal attention - individualized monitoring to ensure needed services are offered, accessible and used.

DEVELOPING A COMPREHENSIVE MENTAL HEALTH SYSTEM

Obviously, many of the hopes and promises of the deinstitutionalization movement have not been realized. Throughout this massive undertaking, however, certain factors affecting future policies in mental health have become evident (4, p. s20).

- o Without sufficient resources, simply changing the locus of care will not create good care, as persons with mental illness do not automatically improve as a consequence of discharge.
- o Mental health systems need to be flexible enough to respond to the cyclical nature of chronic illness and need to aim for a closer integration of institutional and community care systems.
- o Mental health programs need inpatient care facilities for acute phases and various levels of community support for outpatient treatment and care.
- o Good community care may not cost less than institutional care.

A fully developed continuum of care is needed to respond effectively to the diverse needs required by persons with serious mental illness at varying times in their lives. Such a care continuum in the community includes: a range of inpatient and crisis stabilization services, offered through hospitals, nursing homes and acute care facilities; vocational skill training and placement services; daily living skill training; social and leisure activities; a spectrum of housing opportunities; medical and mental health care; case management; and a variety of support

services. Unfortunately, availability of these services is often limited or nonexistent in many communities.

Acute and Crisis Psychiatric Care. For individuals suffering from recurring psychiatric problems and a vulnerability to stress, acute care may be required periodically, often on an emergency basis. Short-term, intensive treatment is provided on an inpatient basis to help patients recover as quickly as possible and to facilitate discharge for further treatment as outpatients. Psychiatric units in general hospitals, nursing homes with specialized mental health care and commmunity crisis programs provide a range of services to meet the differing needs of those requiring inpatient care. Alternatives to involuntary hospitalization for those in acute mental health crisis are being provided by nontraditional inpatient programs, including emergency crisis teams and foster homes or respite housing with supportive services.

Rehabilitative Services. The provision of rehabilitation services, such as social, leisure and employment programs, in conjunction with therapeutic techniques, proves effective in stabilizing and enhancing the lives of those with serious mental illness in the community. Rehabilitative services are especially important following periods of hospitalization or acute episodes of illness. A rehabilitative approach that is able to meet the diverse needs of this population integrates a variety of services, including day programs, vocational skills training and placement and social and leisure activities.

Housing. Housing is a critical component of community care. Without a place to live, the best mental health treatment and the most sophisticated rehabilitation services cannot be effective. A spectrum of residential living arrangements should provide varying levels of supervision depending upon individual needs. Traditional residential models, which are often heavily congregated and staffed, maximize the dislocation of those with mental illness, and incite the greatest community opposition, are being replaced with housing programs that provide stable, dispersed living arrangements and supports.

Supportive Services. In addition to poverty being a common problem, persons with serious mental illness are handicapped by impaired judgment in identifying their needs and developing strategies to meet those needs. To maintain a person with serious mental illnesss in the community, assistance must be available to meet the basic human needs for food, clothing, shelter, personal safety, and general medical and dental care. Assistance also is needed to apply for income, medical, housing and other benefits to which they are entitled. Adequate mental health care provides diagnostic evaluation, prescription and regulation of medication and community or inpatient treatment. Case management services, delivered by a single person or team, provide advocacy, continuity of care and personal help.

GENERAL LEGISLATIVE GUIDELINES

In December 1984, the Mental Health Policy Working Group of Harvard University published findings and recommendations in a paper entitled *Wanderers in a Promised Land: The Chronically Mentally Ill and Deinstitutionalization.* Although the recommendations stemming from this report are broad in perspective, they can provide legislators with general directions for policies affecting those with serious mental illness (4, pp. 62-68).

Community Supports and Services. Policymakers and service providers should ensure that distinct, specialized services required by persons with serious mental illness are provided in the community; that an increased emphasis on rehabilitation stresses care, not cure; and that family and consumer self-help groups are encouraged and strengthened.

Community Mental Health Centers. Community mental health centers should focus more of their resources on providing specialized services to individuals with serious mental illness that are not provided by other community agencies, while state legislatures provide financial support to the maintenance of these needed programs.

Inpatient Beds and Secure Facilities. States must ensure that there are sufficient inpatient beds for those requiring inpatient care on a long-term basis and forensic units to provide care for those with serious mental illness and involved in the criminal justice system. Long-term inpatient beds should be in facilities specializing in psychiatric care.

Intermediate Care Facilities. Programming on a statewide basis should provide for intermediate level care that can respond to the differing needs of patients suffering from serious mental illness. Nursing and board-and-care homes should involve special training of personnel and supports to meet the needs of this special population.

Administrative Responsibility. State legislators effectively can address administrative responsibility for persons with serious mental illness by appointing a single local agency to assume responsibility for planning and coordinating services and by creating a public corporation to administer mental health services on a statewide level.

Fiscal and Management Policies. Policymakers need to develop fiscal/management approaches that promote the most effective utilization of and access to existing resources. This could be achieved through the conversion of closed state hospitals or portions of facilities; the development of better systems of contract management, budgeting and management information; the purchasing of services from vendors rather than direct service provision; and the development of quality assurance standards for community-based programs. States should also consider augmenting the federal Supplemental Security Income Program to improve the subsistence levels of the chronically mentally ill.

Legislative Actions. State legislatures could improve the care and treatment of those with serious mental illness by eliminating barriers in federal and state programs that exclude or prevent the participation of this disabled population, reforming zoning laws that prevent the opening of small homes for persons with mental illness and examining state laws concerning involuntary commitment, particularly regarding the criteria of "dangerousness."

Research Agenda. A research agenda is needed that emphasizes practical problems and decisions faced by state legislators and policymakers, including: cost effectiveness and effectiveness of interventions and treatment settings, innovative management and fiscal models, alternative mental health care and the specific needs of this population and provision guidelines.

THE STATES' RESPONSE IN RECENT YEARS

The mental health system has changed from one that predominately depends on inpatient hospitalization to one that emphasizes a balance between inpatient, outpatient and other needed services. Unfortunately, the treatment continuum necessary to successfully sustain persons with serious mental illness in communities has not materialized in many places. Lack of adequate treatment and care has resulted in repeated inappropriate admissions to hospitals and nursing homes, overuse of emergency rooms and hospitals, undue burden on families, homelessness, and repeated encounters with the correctional system.

In response to these problems, state legislatures across the nation are deliberating the complex issues affecting this population. There has been some improvement in mental health system coordination and service delivery, but few states have comprehensively addressed the needs of these disabled persons.

Comprehensive Service Efforts. Some states are attempting to address the needs of those with serious mental illness in a comprehensive manner. California (1987 Calif. Stats, Chap. 1361) enacted the Children's Mental Health Services Act to establish a comprehensive and coordinated children's mental health system. Massachusetts (1987 Mass. Acts, Chap. 167) appropriated $340 million over a five-year period to improve and expand the state's mental hospitals, community mental health centers and housing programs for persons with serious

mental illness. Minnesota (1986 Minn. Laws, Chap. 342) mandated the development of a comprehensive system of mental health services and appropriated almost $15 million to provide services within the state.

New York and Wisconsin have both attempted to unify mental health services and have affected the delivery of services to those with serious mental illness. Wisconsin (1973 Wis. Stats., § 51.42) and New York (N.Y. Mental Hygiene Law § 41.19, 41.21, and 41.23) authorized a funding formula that supports and complements the placement and coordinating authority for all outpatient services in the hands of local government. With legislation enacted in 1988, Ohio (Substitute Senate Bill 156) will restructure its mental health system by merging clinical and funding authority at the local level.

Components of Care. Many states have attempted to improve mental health services or delivery systems by addressing specific service and delivery components, including residential programming, continuity of care and case management and support services.

Residential Services. A number of states have addressed the need for appropriate residential services for mentally ill persons living in communities. Colorado (1985 Colo. Sess. Laws, Chap. 2341) permanently extended pilot programs for the development of alternatives to long-term nursing home care. Connecticut (1987 Conn. Acts, P.A. 563) required the establishment and maintenance of a network of independent living centers. Indiana (1984 Ind. Acts, P.L. 40) established the community residential care program and mandated the placement of mentally ill individuals in community residential facilities. Massachusetts (1987 Mass. Acts, Chap. 167) appropriated almost $84 million to develop housing for persons with chronic mental illness, including congregate, transitional and permanent housing. New York (1984 N.Y. Laws, Chap. 298) authorized the commissioner of mental health to establish a continuum of community residential services for mentally ill persons, providing up to 100 percent state reimbursement of costs associated with these residential services. New York (1985 N.Y. Laws, Chap. 351) also established residential care centers creating a third type of care for community and institutional placements. The centers provide services and programming for those no longer requiring hospital placement, but unable to handle independent community living. Virginia (1986 Va. Acts, S.J.R. 53) requested that pilot projects be developed to provide support to low-income families with a mentally disabled family member and to use vacant state hospital buildings for supervised domiciliary care.

Continuum of Care. States also have addressed the need for a continuum of care between the hospital and community. Illinois (1985 Ill. Laws, P.A. 84-918) aimed to secure and maintain adequate financial benefits for those individuals admitted to or released from the state hospitals by requiring interagency agreements. Oregon (1981 Or. Laws, Chap. 750) required agreements between community mental health programs and the state hospitals to ensure a continuum of care for patients admitted to and discharged from the state hospital. Illinois (1987 Ill. Laws, P.A. 85-308), Maryland (1982 Md. Laws, Chap. 348 and 1987 Md. Laws, Chap. 576), New Jersey (1987 N.J. Laws, Chap. 116), Oklahoma (1986 Okla. Sess. Laws, Chap. 35), Virginia (1986 Va. Acts, Chap. 309) and Wisconsin (1983 Wis. Laws, Chap. 441) now provide discharge and aftercare services to mentally ill patients released from an inpatient facility into the community.

Case Management. A variety of states enacted legislation in 1987 that defined, enabled, or mandated case management services for those with serious mental illness. California (1987 Cal. Stats., Chap. 1384), Colorado (1987 Colo. Sess. Laws, Chap. 217) and Wisconsin (1987 Wis. Laws, Act 27) added case management services to their medical assistance programs. Arkansas (1987 Ark. Acts, Act 1053) required community mental health centers to use a coordinated case management system. Maine (1987 Me. Laws, Chap. 246) defined case management services and North Carolina (1987 N.C. Sess. Laws, Chap. 422) enabled counties to develop a consolidated case management system. Washington (1987 Wash. Laws, Chap. 7) appropriated funds for an outreach case management team.

Other Services. Various measures have been established by the states to address other components needed to care for persons suffering from mental illness in the community. Arkansas (1987 Ark. Sess. Laws, Act 1053) required community mental health centers to provide community support services as a condition of receiving state funds. California (1985 Cal. Stats., Chap. 1286) established in each county a system of community vocational programs. Hawaii (1987 Hawaii Sess. Laws, Act 216) appropriated funds for a community-based pilot project focusing on providing employment and other community support services. Maryland (1983 Md. Laws, Chap. 268) created the Job Training Partnership Act to assist handicapped individuals, among others, in obtaining employment. Michigan (1986 Mich. Pub. Acts, Chap. 117) provided for alternative treatment programs other than hospitalization. At least 10 states have enacted legislation in recent years to provide assistance or respite to families caring for mentally ill relatives at home, including: California (1987 Cal. Stats., Chap. 558), Connecticut (1987 Conn. Acts, P.A. 432), Illinois (1985 Ill. Laws, P.A. 309), New Hampshire (1987 N.H. Laws, Chap. 32), New Jersey (1987 N.J. Laws, Chap. 119), New York (1987 N.Y. Laws, Chap. 249), North Carolina (1987 N.C. Sess. Laws, Chap. 738), South Dakota (1987 S.D. Sess. Laws, Chap. 203), Texas (1987 Tex. Gen. Laws, Chap. 835) and Washington (1987 Wash. Laws, Chap. 7).

Administration/Delivery of Services. A number of states have acted to ensure coordination of mental health services. Florida (1984 Fla. Stat. § 394) established a statewide network of service districts for the treatment of mental illness and substance abuse, overseen by a network of planning councils. Minnesota (1985 Minn, Laws, Chap. 252) authorized the establishment of a state mental health planning council to advise on matters relating to coordination of mental health services. North Carolina (1987 N.C. Sess. Laws, Chap. 422) enabled counties to develop a single portal of entry for human services and a consolidated case management system. North Carolina (1983 N.C. Sess. Laws, Chap. 383) also gave localities the option of adopting single port of entry/exit systems in their provision of mental health services. South Dakota (1987 S.D. Sess. Laws, Chap. 394) created the Mental Health Planning and Coordination Advisory Board to advise on increased coordination of planning and service delivery efforts. Virginia (1987 Va. Acts, Chap. 79) clarified that agreements between community services boards and local human service agencies are to be jointly developed, implemented and reviewed by participating agencies. Washington (1982 Wash. Laws, Chap. 204) defined the roles of the state, counties and the individual service providers in the state mental health system and delineated responsibilities for continuum of care and coordination.

Funding. States also have taken different approaches to funding community mental health services. Connecticut (1985 Conn. Acts, P.A. 85-472 (special session)) established a community residential revolving loan fund to construct, purchase or renovate residential facilities. Florida (1985 Fla. Laws, Chap. 253) and Illinois (1986 Ill. Laws, P.A. 1373) established trust funds for the benefit and support of handicapped individuals. Louisiana (1981 La. Acts, P.A. 770) established the Community Residential Program Development Fund to provide loans to cover initial expenses of starting community residential programs. Minnesota (1985 Minn. Laws, Chap. 9 (special session)) established a statewide program to assist counties in providing services to the chronically mentally ill by making grants to counties, with 25 percent of the costs financed by the state after mid-1987. New York (1974 N.Y. Laws, Chaps. 620 and 621 and 1983 N.Y. Laws, Chap. 816) provided local governments with 100 percent state reimbursement for various services provided to the deinstitutionalized mentally ill living in the community. Texas (1985 Tex. Gen. Laws, Chap. 500) allowed for the use of funds to renovate existing community center facilities, as well as to construct new facilities through liens on a center's property. In 1987, at least 11 states required clients or family members to pay for at least a portion of service costs.

A variety of states developed alternative funding sources to pay for mental health services in 1987. California (1987 Cal. Stats., Chap. 945) and Oregon (1987 Or. Laws, Chap. 902) established a check-off on tax returns for Alzheimer's disease programs; a joint effort between New Jersey (1987 N.J. Laws, Chap. 57) and New York will use tourist fee revenue for aid to

homeless persons; and Alaska (1987 Alaska Sess. Laws, Chap. 48) reconstituted its mental health land trust to fund the state's mental health system.

FUTURE TRENDS AND IMPLICATIONS

Today, persons who suffer from severe, persistent or recurrent mental illness with residual social and vocational disabilities, are one of our nation's most pressing concerns. The mental health policies of the past two decades and the evidence of unserved populations suffering from serious mental illness constitute a public health crisis. Legislators will play an important role in developing coherent policies to create a coordinated mental health system in the future.

Future service and delivery systems must be revised to meet the changing needs of new and emerging populations, such as young adults who are difficult to treat in the "traditional system," mentally ill persons who are homeless, and individuals suffering from mental illness and AIDS. Resource constraints will force states to prioritize those populations most in need and probably will include the elderly, those with long-term serious mental illness who are generally in the community but experience occasional hospitalizations, and those individuals who are "difficult-to-treat," such as persons who are homeless, violent, or resistant to traditional treatment. The future mental health system also will continue to become more decentralized and efforts will be made to access services through broad-based programs such as housing, income support and social services.

States need to take a system-wide approach to coordinating mental health services into a rational, cost-effective system with clear roles and responsibilities for serving those with serious mental illness. Higher inpatient costs will force states to coordinate care so consumers will receive the community services that will prevent them from cycling into and out of the hospital. Coordinated care also will ensure that adequate and appropriate services are provided to those in need in a timely fashion.

State and local governments will continue to face major funding difficulties in financing mental health services. Efforts can be initiated by state, local and federal governments to remove incentives toward more restrictive forms of care and to remove barriers that discriminate against those suffering from serious mental illness. Economic constraints also will force states to promote the most effective utilization of existing services. Rising mental health costs may lead many states to consider prospective payment and capitation systems for the financing of inpatient and outpatient care.

There has been a slowly growing trend, demonstrated by several state and national initiatives, to address comprehensively the needs of those with serious mental illness. Reports of uncoordinated delivery systems, lack of services and inadequate funding have placed and will continue to place increasing pressure upon state legislatures to improve mental health services and delivery systems for this greatly disabled population. States must realize, however, that a fully developed continuum of care is needed in order to be truly responsive to the complex and diverse needs of this disabled population.

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